

Julie, Remy and Tia Sharp who was stillborn at 40 weeks plus 9 days with no explanation, on 31st August 2010

Issue 4 March 2012

Spotlight on Sands

CAMPAIGNING NEWS BULLETIN

Introduction

Welcome to our latest issue of *Spotlight on Sands*, bringing you up-to-date on all our campaigning news.

Sands launched its latest report in the House of Commons in January this year *Preventing Babies Deaths: what needs to be done*. In it we told the personal stories of bereaved parents to highlight the broader issues of what needs to be done to prevent avoidable baby deaths.

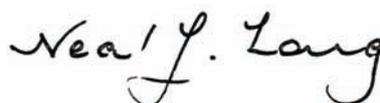
The stillbirth rate in the UK has remained unchanged for a decade. In that time other similar income-rich countries have cut their stillbirth rates by up to 40%. While different healthcare systems and different demographics make it hard to compare even similar countries, there are some obvious and clear roads to improving care and saving lives. We outline them in our report.

The launch was followed swiftly in March by the Stillbirth Workshop, co-hosted by Sands and the

Department of Health, which aimed to bring the experts together to discuss what action must be taken. Several working groups have emerged from this meeting and we look forward to supporting their progress in the future.

Ultimately, it is the powerful voice of parents and a collective public mood for improvement to the unacceptably high rate of stillbirth in the UK, which has put the issue of perinatal death increasingly on the public health agenda. With the landscape of the NHS on the cusp of radical change, it is paramount to keep the lives of babies, the most vulnerable members of our society, in the spotlight.

We are grateful to you for your continued support in keeping this a national health priority.



Neal Long, Chief Executive, Sands

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Diary Date

Sands will be a key speaker at the upcoming **All Party Group on Maternity meeting**

Monday 14th May 2012, 7pm, Portcullis House, Westminster on the topic of Adverse Birth Events. If you are interested in attending, please email tara.macdowel@uk-sands.org.



Stillbirth & neonatal death charity

Preventing Babies' Deaths: report launch

On Wednesday 18th January Sands launched its major new report *Preventing Babies' Deaths: what needs to be done* at a parliamentary reception in the Members' Dining Room, House of Commons, where 75 MPs and 150 other guests, including key researchers, clinicians, health officials, members of Royal Colleges and Heads of major charities joined Sands parents, supporters and staff.

The reception was hosted by Dr Daniel Poulter MP, obstetrician and Chair of the All Party Parliamentary Group on Maternity. We were also delighted that the Parliamentary Under Secretary of State for Public Health, Anne Milton MP, attended and gave a very supportive speech, highlighting in particular the importance of breaking down the 'taboos' around stillbirth and raising public awareness. Neal

Long, Chief Executive of Sands, provided guests with a summary of the report's contents and key issues, and Sands parent, Colin Pidgeon described the devastating impact of the death of his baby daughter, Daisy.

Throughout the day the media also highlighted the launch of the report, with widespread coverage across the BBC and ITV, as well as the national press, including: *The Sun, Daily Telegraph, Guardian, Daily Mirror* and *Independent*. The story was also picked up locally across the UK with Sands spokespeople being interviewed on over 30 radio stations and the report featuring in over 100 regional papers.

With such a positive response to the new report, we intend to keep up the momentum and ensure that everything possible is done to keep stillbirth and neonatal death

(the death of a baby within the first four weeks of life) in the spotlight.

"We want to see real national commitment to tackling this ignored tragedy and preventing all avoidable baby deaths in the future." Neal Long, Chief Executive, Sands

"After Erin died, I got a letter from the hospital and it described all the scans I'd have if I got pregnant again. But it's too little too late. I wanted Erin. She wasn't a test run."

Louise McGeechan



Guests gather in the Members' Dining Room to hear Neal Long, Chief Executive of Sands



Neal Long, Chief Executive, Sands with Anne Milton MP and event host Dr Daniel Poulter MP



Members of Tunbridge Wells Sands group with Greg Clark MP (centre) and Kate Anker, Chair of the Trustees, Sands (far right)

The media coverage of the report highlighted some of the key messages from the report:

- ▶ As many as 1,200 stillbirths could be avoided every year in the UK: these are the 1,200 babies who are born, and die, at full term (after 37 weeks)
- ▶ Routine antenatal care is failing to detect many babies who are at risk of dying
- ▶ Many of these deaths could be avoided through a combination of more research, better care and greater awareness of the risks of stillbirth

Sands campaigns to change DWP Guidance on Maternity Allowance

Sands was extremely concerned last year to hear that some mothers whose babies were stillborn, were being refused maternity benefits by some local benefit offices.

Following consultation with the Department of Work and Pensions, and in conjunction with the charity, Working Families, Sands is delighted to announce that the Department is making changes to Maternity Allowance Guidance to ensure

mothers of stillborn babies receive the benefits they are legally entitled to.

In future, bereaved parents will only have to produce evidence of stillbirth by way of a Certificate of Stillbirth when claiming Maternity Allowance and Statutory Maternity Pay. While the guidance is being

updated should any parents whose baby is stillborn and who have been issued with a stillbirth certificate be denied benefits they should contact Prabhavati Mistry at the Department of Work and Pensions who will look into their case. Email: Prabhavati.Mistry@dwp.gsi.gov.uk

DWP

Department for Work and Pensions

Parent case study

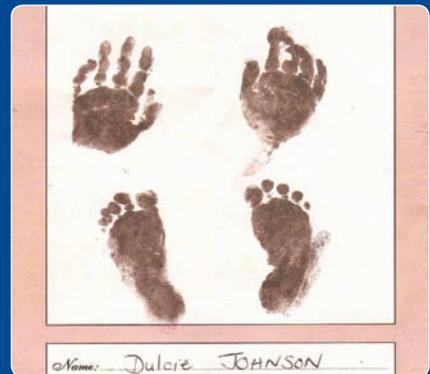
We are grateful to all the parents who highlight issues to us, and who agree to share their stories to illustrate where the system may have failed. Our benefits campaign was helped hugely by bereaved mother Rebecca Johnson, who contacted Sands after being refused maternity benefits.

Sadly, Rebecca's baby girl Dulcie Rebecca Johnson was stillborn weighing 11lbs 8oz on 15th July 2011. Dulcie had been due, as stated on her Mat B1 form, on Thursday November 3rd 2011. As required by the Stillbirth Act, Dulcie was certified and registered as a stillbirth. However, the Benefits Office refused Rebecca's claim for

maternity allowance, which she was entitled to, as they used a different method for calculating a baby's due date. Using their calculations, Dulcie was born pre 24 weeks, and not therefore stillborn, despite the evidence of a stillbirth certificate.

Rebecca then embarked on several months of campaigning, producing a detailed report on her personal case and contacting her local MP Richard Bacon, her obstetrician, the Department of Work and Pensions and even David Cameron. Rebecca was able to share her case with Sands, who approached the Department of Work and Pensions on her behalf.

Without doubt this evidence was instrumental in their decision to change the Maternity Allowance Guidance, and we are very grateful to Rebecca. We are also delighted to report that through her dogged determination she did eventually receive the benefits she was entitled to.



Hand and footprints of Dulcie Rebecca Johnson, stillborn on 15th July 2011

Tackling smoking in pregnancy: a policy seminar

On March 8th Sands, a number of baby charities, the UK Centre for Tobacco Control Studies and Action on Smoking and Health (ASH), organised a Smoking in Pregnancy Policy Seminar, to highlight the risks of smoking, current research in the field, and the challenges faced by those delivering smoking cessation programmes. Attending were key researchers, health professionals and policy makers.

The Tobacco Control Plan for England, published in March 2011,

aimed to reduce smoking in pregnancy from 14% to 11% by 2015. The real rate is currently likely to be much higher given under-reporting. The latest data shows smoking rates among mothers have fallen least in the past five years among the most disadvantaged mothers, so worsening health inequalities. Smoking rates among teenage mothers has fallen by only about one fifth.

Smoking causes 300 perinatal deaths every year in the UK; 19,000 low birth weight babies, and 2,200 premature

births. It also causes birth defects. Up to half of pregnant smokers have mental health problems. Smoking cessation midwives say they face challenges due to widespread ignorance about the risks of smoking in pregnancy.

The day, which was hosted by Liz Woodeson, Director of Health and Wellbeing at the Department of Health, concluded with a commitment to set up a working group focusing on tackling this important public health issue.

What needs to be done

The scale of baby deaths in the UK is shocking. Seventeen babies are stillborn or die shortly after birth every day, with stillbirth being the largest contributor to child deaths under the age of five years. Our new report *Preventing Babies' Deaths: what needs to be done* describes the devastating impact these deaths have on parents and their families, and highlights the areas where we believe progress can be made that could save hundreds of babies' lives.

Our key areas of concern and recommendations for improvement and change are:

How many babies die and why?

Good data and audit are essential to advance understanding of why babies die and to improve care. But key health policy work for collecting national perinatal data was suspended in April 2011. As a result possibly two years worth of data may have been irretrievably lost.

The Clinical Outcome Review Programme Maternal and Newborn Health is due to be resumed in April 2012. It is essential that it be supported in its work, if it is to gather high-quality data from which lessons can be learned.

A public health issue?

Without greater awareness of the risks of their baby dying how can prospective parents make informed choices about their health and pregnancy care? Awareness alone can help prevent deaths. Meanwhile despite government initiatives, inequalities in perinatal mortality persist.

A national forum should be established to share understanding of the public health aspects of perinatal death and develop public health and education messages.

New research is needed to understand social inequalities in perinatal death.

Research and new interventions

A third of stillborn babies are perfectly formed and born at gestations when they might safely be delivered. But

routine antenatal care is failing to detect far too many babies who need help. New reliable, diagnostic tests are urgently needed. Stillbirth is where cot death was 30 years ago. There is still so much to be done.

▶ **Government research funding bodies must direct funds expressly into the causes and prevention of unexplained stillbirth.**

Review: the key to improving care

Sometimes babies die because of failures of care. Yet lessons about what went wrong are too often overlooked and opportunities to improve care are missed. Standardised review would help those who organise and deliver health care to learn from mistakes and make sure they implement best practice.

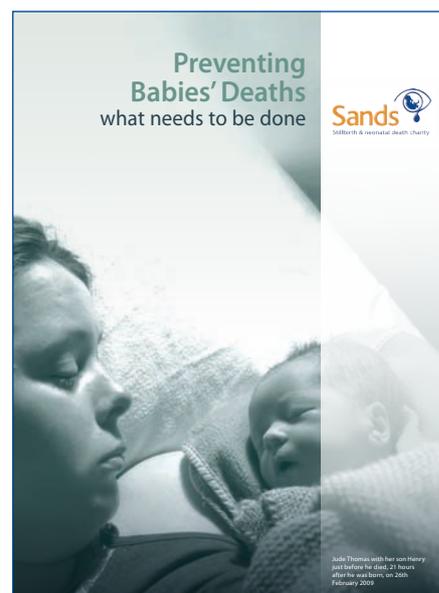
▶ **A national standard for reviewing perinatal deaths must be developed and followed in all Trusts. This needs to incorporate the parents' perspective.**

▶ **The quality and effectiveness of hospital level perinatal mortality review must be audited.**

▶ **The Clinical Outcome Review Programme must re-introduce a programme of national confidential enquiries into perinatal deaths.**

Staffing for quality and safety

Without adequate staffing and skills mix how can services be safe? Under-resourcing across the board in maternity and neonatal care has very real and tragic consequences. Yet calls



to achieve even minimum staffing levels are still not being met.

▶ **Urgent action is needed to ensure minimum levels of staffing and the right skills mix in all areas of perinatal life and death - as outlined by the relevant professional bodies.**

▶ **Medical training for doctors and midwives must include a module on the risks and impact of perinatal death to improve awareness and understanding.**

Care after a death

The quality of the care that thousands of bereaved families receive every year when their baby dies has long-lasting effects. At a time of overwhelming distress parents need the right support from trained staff in making important choices about the precious and painfully short time they have with their baby.

▶ **Managers and service commissioners must fund and organise bereavement services in line with Sands' Guidelines for Professionals, and to include high quality perinatal pathology services.**

▶ **There must be support for the development and implementation of a Bereavement Care Pathway, outlining minimum standards of care for bereaved families.**

▶ **Trusts should adopt the national post mortem consent form and improve training in consent taking in tandem with the form.**

Stillbirth Workshop March 2012

Following on from our January launch, on Thursday 1st March, Sands and the Department of Health were pleased to bring together a select group of key experts and professional bodies for the first-ever national workshop in England to focus on stillbirth prevention.

In support of the event, Anne Milton MP said, "The death of a baby is devastating for parents and their families. By focusing on four key areas - improving perinatal reviews, commissioning, identifying the baby at risk and raising public awareness of stillbirth - this workshop

presents a real opportunity to make a difference. I feel personally associated with this issue, not because I have suffered with the loss of a child or a stillbirth, but because I feel very fortunate to be the mother of four children.

"Today needs to represent a watershed in turning this round, for the people who have suffered and will always suffer from the loss of their child and also to stop this happening to others." There were a number of actions agreed at the meeting, and 'next steps' are now being drawn up.

Keep an eye on our website for details. www.uk-sands.org.



Rachel and David Hirst with daughter Imogen, stillborn on Valentines' Day 2011

Parent case study

Trish Simpson is a member of the Sands Campaigning Voices group, and also Sands Swindon. She wrote to her local Conservative MP for North Wiltshire, James Gray, to highlight her personal story, her involvement in the local group, and to arrange to meet with him at the Westminster parliamentary reception.

James Gray was very supportive and keen to help in a practical way. In the first instance, he signed our Early Day Motion and issued a press release to the local media in Swindon to raise awareness of stillbirth

and the new report. Trish is in contact with him about attending a fundraising event in April as well as supporting the establishment of a new local group. She is also keeping him up to date with our campaigning priorities.



Sands Campaigning Voice Trish Simpson and husband Dr John Simpson with local MP James Gray

Sands Campaigning Voices group

We are continually grateful to all the bereaved parents and families who support Sands in so many ways.

In 2010 we established our Sands Campaigning Voices group to bring together people who were keen to push for change at a local and national level. We have over 300 'Voices' from all across the UK. Around 50 attended the Westminster launch of the *Preventing Babies' Deaths* report, and many more contacted their local MP to notify them personally about the parliamentary reception and the issues in the report.

As a result of this local campaigning, many MPs are actively supporting Sands at constituency and government level: some have raised questions in the House, signed our Early Day Motion or written to the Health Minister; others have visited local Sands groups, local maternity units or helped with local publicity.

The need for research

Our focus for the spring and summer will be on the need for research funding. Sands is concerned about the lack of research into what is causing so many babies to be stillborn each day.

There are a small number of research studies currently underway which are potentially related to stillbirth but the majority of these have broad remit that encompass many aspects of maternity care. Preventing stillbirth is a potential by-product of the work rather than a primary focus. We are urging Government research funding bodies to direct funds expressly into the causes and prevention of stillbirth. **If you would like further information on getting involved with this issue, please contact:**
tara.macdowel@uk-sands.org

Devolved governments taking the lead

Following Sands campaigning in 2009, the **Scottish Government** established an expert working group to look specifically at reducing stillbirths. The group has met several times and is developing parent information leaflets advising about fetal movements, and national guidance for Scotland for the detection and management of growth restriction. They also hope to standardise perinatal mortality reviews with the aim that lessons learned should not be lost, and to

take forward the development of specific online learning modules on stillbirth which will be available to all maternity services staff.

In **Wales**, we are pleased that the Health and Social Care Committee has recently decided as a part of its programme of one-day inquiries, to devote a day to look at reduced fetal movements, poor growth and stillbirth in Wales. We hope that this could lead to a similar group to the one in Scotland.

A number of MPs from **Northern Ireland** attended our Westminster launch in January and have since written to the Minister for Health to highlight the *Preventing Babies' Deaths report*, and to push for the establishment of a specialist group in Northern Ireland.

Visit www.uk-sands.org to read further news as it develops.

Support us as a Sands Parliamentarian

The Sands Parliamentarians Group is an informal group of MPs, MSPs, AMs, MLAs and Peers who are committed to supporting the issues that are of concern to Sands, because they are the issues that matter to the bereaved families we represent.

The group will help us to raise the issues at a national policy level, to stimulate debate and encourage collaboration to create a national strategy to reduce the number of stillbirths and neonatal deaths.

For more information contact:
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Campaigns and Public Affairs
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0208 973 3691

About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Since that time we have supported many thousands of families whose babies have died, offering emotional support, comfort and practical help. Sands today operates throughout the UK and focuses on three main areas of work:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- ▶ Helpline for parents, families, carers and health professionals
- ▶ UK-wide network of support groups with trained befrienders
- ▶ Online forum and message boards enabling bereaved families to connect with others
- ▶ Website and a wide range of leaflets, books and other resources.

We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care

We undertake a comprehensive programme of training, workshops and talks for health professionals based on the Sands Guidelines which give practical guidance on how to meet parents' needs and provide good bereavement care.

We promote and fund research that could help to reduce the loss of babies' lives

In spite of medical advances, the shocking reality is that each day in the UK 11 babies are stillborn and six die within the first 28 days of life. Through our *Why17? campaign*, we are raising vital funds for research, while challenging the Government to address these individual tragedies as a matter of urgency and priority.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services we offer.

Helpline: 020 7436 5881
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Web: www.uk-sands.org
Web: www.why17.org
Email: info@uk-sands.org

Charity registration number 299679
Scottish Charity Registration Number: SC042789